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Abstract

This article considers proposals to reform the law in response to recent high profile cases concerning the medical treatment of children, currently before Parliament in the Access to Palliative Care and Treatment of Children Bill 2019–21. It considers the proposed procedural change, to introduce a requirement for mediation before court proceedings, and argues that dispute resolution processes should be a matter of good practice rather than enshrined in law. It argues that the proposed substantive change to determination of best interests would not result in different outcomes because the best interests analysis co-exist with the legal and professional duties of doctors to children in their care. It argues that if there is to be reform of the law it needs to follow from a comprehensive review of all the issues in which the minimum standards imposed by law fit together with good practice standards and not in response to individual cases.

Keywords

Medical treatment of children, Access to Palliative Care and Treatment of Children Bill 2019–21, mediation, legal and professional duties

Introduction

Sympathy for the parents of children whose life-support has been withdrawn following high-profile and highly charged court cases gives some weight to their claims that the law and legal processes need to change. The parents of Charlie Gard have been the most determined, working together with NHS professionals, ethicists, and lawyers to develop Charlie's Law. Similar proposals for changes to the legal processes were made by a supporter of the parents of Alfie Evans.¹ Whilst the parents of Tafida Raqeeb,² with whom MacDonald J agreed that it was in her best interests for ventilation to be continued, expressed the view that the Children Act 1989 needed to be revised to give better protection to parental rights. There is currently no specific legislation addressing the provision of medical treatment or medical decisions with respect to children. The principles governing decisions concerning the provision of medical treatment to children have developed through the case law within the framework established by the Children Act 1989.³ This article considers proposals to reform the law in light of these recent high profile cases in order to contribute to the wider debate over reform of the law. It argues that reform of the law is not necessary as the common

law, within the framework provided by the Children Act 1989, has the ability to adapt to the changing social, legal, and cultural context. However, if there is to be reform it needs to follow from a comprehensive review of all the issues in which the minimum standards imposed by law fit together with good practice standards and not in response to individual cases.

The Access to Palliative Care and Treatment of Children Bill 2019–21 (the Bill) currently before Parliament was introduced as a private members Bill to the House of Lords by Baroness Finlay in January 2020, with specific reference to the case of Charlie Gard.⁴ Progress of the Bill, which was not given government support, was disrupted by the COVID-19 pandemic and is yet to reach the committee stage. This Bill is the third occasion on which legislation has been proposed which would change the law governing medical treatment decisions concerning children, influenced by the views of parents in recent high profile cases.

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Charlie Gard's parents, Connie Yates and Chris Gard, have argued for a change to the law informed by their experience of the litigation against Great Ormond Street Hospital for Sick Children (GOSH) to try to prevent the withdrawal of life-sustaining treatment from their son.⁵ Charlie's Law seeks to change processes to prevent cases reaching court by access to clinical ethics committees, medical mediation, and providing parents with their child's medical reports. They want better advice and support for families on ethics and rights, independent second opinions, and access to legal aid. Substantively, they want better protection of parental rights. Reflecting the argument advanced on their behalf on appeal, they seek to restrict the involvement of courts to cases where the child is at risk of significant harm. They have expressed the view that the best interests analysis of the current law provides a 'broad platform for the overruling of parent's wishes' and that there was insufficient evidence that providing nucleoside therapy to Charlie would have caused him significant harm, so that this threshold would have prevented the judge from deciding his case and enabled them to have taken Charlie to the US for a trial of innovative therapy.

Clause one of the current Bill concerns palliative care services in the NHS and dominated debate in the House of Lords. Clause two, concerned with disputes over the medical treatment of a child, would enact procedural change – introducing a requirement for mediation before court proceedings – and substantive change to determination of best interests and the duties of doctors to children in their care. These are considered in turn to argue that dispute resolution processes should be a matter of good practice rather than enshrined in law and that the proposed substantive change would not result in different outcomes because, as with the current law, best interests analysis exists alongside the legal and professional duties of doctors to children in their care.

Mediation

The first reform proposal in response to the campaign for Charlie's Law took the form of amendments introduced by Lord Mackay to the Mental Capacity (Amendment) Bill to provide for access to a clinical ethics committee and for medical mediation to be made available when a dispute has arisen.⁶ Lord Mackay explained that this provision, aimed at preventing cases reaching court unnecessarily, was a 'proportionate and long-overdue measure' which he hoped would be the first step to enactment of Charlie's Law'.⁷ However, as an amendment to the Mental Capacity Act 2005 it would only have applied to patients aged

16. The amendments were not in the Act when it was passed in 2019.

The provisions of the current Bill would apply when consideration is being given to an application to the High Court under the Children Act 1989 or under the inherent jurisdiction of the High Court for an order which has the effect of approving the giving or withdrawal of any form of medical treatment for a child. Except in urgent cases, an attempt would first have to be made to resolve the differences, between the hospital and persons with parental responsibility or interest in the welfare of the child, by mediation with an independent mediator. Requiring mediation before a court application is made has a precedent in family law in s.10 of the Children and Families Act 2014 and Family Procedure Rules 3.5–3.10 which apply to private law disputes such as arrangements over where a child is to live or specific issues that have arisen with respect to the upbringing of the child, for example, his or her education or religious upbringing.⁸

Use of mediation has been encouraged by judges as a means by which to identify common ground. In the high court in Charlie Gard's case, Francis J expressed the view that mediation might resolve the issues in some cases, in others it might lead to a better understanding between the parents and clinical team.⁹ That was duly noted by GOSH which undertook to consider mediation in future cases.¹⁰ When, following further tests, Charlie's parents agreed that it was no longer in his best interests to undergo a trial of the therapy, GOSH offered mediation as a way by which to agree with his parents the end of life plan for Charlie.¹¹ The offer was not accepted and the end of life care of Charlie provided following declarations made by Francis J. Prior to the court proceedings, there were three unsuccessful attempts at mediation between the clinical team at Alder Hey and the parents of Alfie Evans.¹²

Although it did not avoid the need for a court hearing, mediation meetings held between the parents of 9 year-old X and her treating team at GOSH in relation to her future treatment in the event of a deterioration in her condition had provided her parents with the opportunity to voice their concerns and enabled an exchange of information including from independent experts. As a consequence, when the court proceedings commenced the issues had narrowed, agreement reached on the withholding of a number of invasive procedures, leaving the question whether it was in X's best interests to receive a form of non-invasive ventilation and to be admitted to intensive care.¹³ However, notably, in this case Russell J was critical of the referral of X's case to the clinical ethics committee at GOSH without involvement of her parents. Like mediation, referral to a clinical ethics committee might be good practice in

the attempt to clarify the issues and avoid litigation. However, Russell J observed that there is no guidance on the constitution or conduct of Ethics Committees. In the view of the judge, it could not be good practice for Ethics Committees to consider cases without the participation of, or consultation with, patients or their families to ensure that their views are taken into consideration. Failure to involve X's parents had contributed to their anxiety and feelings of alienation and exclusion.¹⁴ For legislation to mandate a trial of an alternative dispute resolution alone, as the current Bill does, does not ensure good practice in its provision.

When communication is breaking down and trust eroding, the commencement of legal proceedings can fuel the conflict and entrench polarised positions.¹⁵ In contrast, mediation has the potential to address the real causes of the dispute and reduce the alienation between parents and the treating team.¹⁵ Mediation is one of a variety of responses available to maintain or nurture trust and communication in difficult cases when there are different opinions about a child's best interests. Guidance issued by the Royal College of Paediatrics and Child Health in response to the recent high profile cases directs practitioners to the range of support available to them and to parents to prevent and manage conflict including second opinions, clinical ethics committees, and mediation.¹⁶ This guidance could be further developed to help practitioners determine which of the range of support mechanisms may be appropriate in an individual case and also the values which should guide them in their response to a developing dispute. Mediation offers one method by which disagreements might be resolved and should be used as a matter of good practice in appropriate cases rather than legally proscribed for all.

Best interests, significant harm and reasonable refusal

The current Bill would require a court to 'assume, unless the contrary is clearly established' that medical treatment proposals put forward by any person holding parental responsibility for the child are in the child's best interests. The explanation, given in the notes, is that this provision 'reinforces the socio-medical norm' that those holding parental responsibility are seeking to act in the best interests of the child.¹⁷ At first sight, the clause as originally drafted seems to go no further than to reflect the position adopted in the cases in which it is accepted that the child's parents are genuinely acting according to their heartfelt judgement of their child's best interests as the ones who know the child best. However, the clause goes further to create an as- or pre-sumption that the child should be treated as the parents propose, a presumption that requires clearly

established evidence to the contrary in order to be rebutted. Despite the burden of proof this would introduce being unclear and the provision being tantamount to a reversion to parental authority, it is unlikely to result in different outcomes. This is because by the time the issue is brought before the court, as currently, the Trust will have evidence from the child's treating team, second opinions, and independent experts to rebut the presumption.

Further, an amendment suggested by Baroness Jolly to be added at the Committee stage would require the court to 'consider' any treatment proposal presented by any person holding parental responsibility 'unless contrary evidence is established that the proposed treatment poses a disproportionate risk of significant harm.'¹⁸ Inevitably, judges already 'consider' the treatment proposal presented by the holder of parental responsibility given that is the issue under dispute. Raising similar burden of proof issues the amendment would require the provision of the treatment proposed by the parents unless 'established' by 'contrary evidence' that it presents a 'disproportionate risk of significant harm'. The merits or otherwise of a significant harm, rather than best interests, threshold has been debated at length in the academic literature and are not repeated here.¹⁹ Here it is argued that the introduction of a significant harm threshold together with clause 2(5), directed at the legal duties of doctors to children in their care, would not result in different outcomes.

Clause 2(5) provides that a doctor cannot be required to provide a specific medical treatment to a child when there are reasonable grounds to refuse to do so.²⁰ This would change the current law that neither parents nor the court can require a doctor to treat contrary to their clinical or professional judgement. This clause raises first the question of the difference between the current law and the proposed amendment and then the question of how this clause would work with the presumption of the parental view of best interests and, if introduced, the significant harm threshold.

The current law is frequently stated but rarely applied given that in the majority of cases the judiciary have agreed with the conclusion of the treating team on the best interests of the child. The principle originated in the judgment of Lord Donaldson MR in *Re J* (1991),²¹ repeated as part of his ratio in *Re J* (1993).²² In the later case, Lord Donaldson also said that if there were another qualified doctor willing, and with the facilities, to treat the child as the parents wanted, the Trust would have to consider its current responsibilities to the child and to other children who may need its facilities, whilst the parents would have to consider carefully the advice and consider any risks involved in a transfer.²³ In the recent case of *Tafida*

Raqeeb, MacDonald J stated that the consequence of his conclusion that continued ventilation was in her best interests was that it had to be continued either within the NHS Trust or by the hospital in Italy where the team were, in their professional judgement, prepared to continue ventilation.²⁴ In *Re MB*, Holman J concluded, despite the unanimous medical opinion of the treating team and independent experts, that it was in MB's best interests for the current care he was receiving to be continued. Applying the principle that a judge could not require doctors to treat contrary to their professional judgement,²⁵ Holman J stated his conclusion but that he could not make an order or declaration to that effect.²⁶

Given that in the majority of cases judges agree with the conclusion of the treating team as to the child's best interests, the conclusions in *Re MB* and in relation to Tafida Raqeeb being rare in the body of case law, there is a lack of authority as to the nature of the principle. Although the judges use the terms interchangeably, presumably professional judgement is wider than clinical judgment, the latter reached through the application of clinical knowledge and experience, the former embracing professional guidance and value 'judgements about what is of value in life, how best to promote the child's interests, and how different or competing interests should be weighed against each other'.²⁷ Furthermore, medical treatment involves numerous judgements. Doctors must fulfil the standard of care in the diagnosis, identification of treatment options and provision of treatment and make a professional judgement about which of the available treatment options is in the best interests of the child. When a parent has a different view about best interests, doctors will have to decide whether, in their professional judgement they can accede to the parental wishes. In some circumstances, they may reach a professional judgement that they cannot treat, or continue to treat as the parent wishes them to do.

It is reasonable for a doctor to refuse to treat a child in a way that is not supported by a competent body of professional opinion. For example, in the April hearing of the future medical treatment of Charlie Gard, there was not the evidence before the court that a trial of nucleoside therapy was supported by a competent body of professional opinion.²⁸

For a doctor to refuse to provide a treatment option which is supported by a competent body of professional opinion but not in their professional judgement best for the child may be unreasonable or may be within the range of reasonable responses. In such a case, given there is a competent body of professional opinion prepared to treat, provision of treatment is not precluded. The view of the practitioner prepared to treat would be

considered alongside the risks of transfer, as occurred with respect to the care of Tafida Raqeeb.

Where the Trust has referred the matter to court because the treating team can no longer treat as the parents wish because to continue to do so is 'professionally wrong' or 'so contrary to [the child's] best interest that it would be inimical to their respective Hippocratic oaths to treat her and would therefore be unethical',²⁹ refusal would not seem unreasonable. It is difficult to see that a conscientious doctor, acting competently, supported by second opinions, independent experts and acting in accordance with professional guidance, would be considered to be acting unreasonably in refusing to provide the treatment according to parental wishes as in many of recent cases concerned with the withdrawal of life-sustaining treatment from a child.³⁰

Putting the clauses together, doctors can reasonably refuse to provide treatment when they disagree with the parent's view that treatment is in the best interests of the child. If there is another practitioner who in the exercise of their professional judgement is prepared to treat transfer should be considered but the court cannot require the doctor to treat contrary to their professional judgement or reasonable refusal. It may be reasonable for a doctor to refuse to treat a child contrary to their legal and professional duties to the child even when the risk of significant harm is not disproportionate. The nature of the legal, ethical, and professional duties owed by doctors to children in their care should be the focus of any review of reform to the law.

Conclusions

Sympathy for parents of seriously ill children who disagree with their child's doctors about their medical treatment is understandable but cannot provide the basis for law reform. In 1981, the case of *R v Arthur*, in which Dr Arthur was prosecuted following the death of a newborn baby with Down's Syndrome for whom he had instructed nursing care only, prompted the Limitation of Treatment Bill. It proposed that no criminal offence would be committed when a doctor withheld or withdrew treatment from a child, to which the child's parents had given consent, and two doctors certified that the child suffered from severe physical or mental 'handicap' that was either irreversible or of such gravity that after receiving all reasonably available treatment the child would enjoy no worthwhile quality of life. In assessing the child's prospective quality of life, doctors would be directed to consider a number of factors including anticipated pain and suffering, the child's potential to communicate and, reflecting the facts in *R v Arthur*, the willingness of

his or her parents to care for the child. The Bill, which did not pass into law, reflected the concerns of the time, the potential criminal liability of doctors, that children with disabilities may not have a worthwhile quality of life and that the care of disabled children, given attitudes to disability and lack of support, was burdensome.

Legislation which no longer reflects current values can be reformed, although as we have seen with the Abortion Act 1967 and in relation to assisted dying, governments avoid grappling with controversial matters of life and death. Legislation on medical issues requires broad frameworks such as those provided by the Children Act 1989 and Mental Capacity Act 2005 which, like the common law, are able to adapt to the changing social, legal, and cultural context. Whether the law and legal processes governing the provision of medical treatment to children is best left to the common law or needs a specific legislative framework needs to be decided following a comprehensive review of all the issues informed by a broad range of experiences. Consideration needs to be given to the relationship between the minimum standards imposed by the law and good practice guidance and to the legal and professional duties of doctors as well as the best interests standard. Legislation which so profoundly affects the lives of children, their parents and families, and health professionals should not be framed in reaction to an individual case however sympathetic we are to the plight of the devoted parents of a seriously ill child.

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